

The Greening of a Health Advocacy Organization

by Beatrice Greenbaum, M.A., M.P.A.

When invited to write an article on grass-roots advocacy organizations and how a community conceives, delivers, and nurtures a healthy one, my first response “why not?” was my typical approach to any new venture or request. Three areas need to be explored: what are grass-roots organizations; why do they exist; and how are they built?

The very words grass roots when applied to community organizations trigger a stream of stereotypical images, replays of the plots of old-time favorite movies. Challenged by pressing issues of local importance often polarizing and one-sided, a self-starting unit of like-minded citizens roused to action by a hero-type leader meets to talk, to deliberate, to listen to their neighbors’ voices, to seek solutions and reach consensus. Now fill in the picture with a Village Green, Town Hall, Community Center, and a picket fence or two — and there you have it: the perfect grass-roots setting in which to “think locally, act locally” in true democratic spirit.

However, given the areas and population densities of an urban center, how would city folk fare? Would they not be disenfranchised and lose all opportunities to have their ideas and beliefs help shape the public policies that affect them?

If changes come from an engaged citizenry, if public conversations foster self-reliance and overcome differences and diversities, how ought we not find a crack in the urban cement for even a few blades of grass to peak through?

At no time would the loss of an option to advance deliberative democracy be felt more keenly than in our present drastically changed and rapidly changing, disoriented health-care environment. At no time would the need for action be more imperative. In the recent past, health care issues confronting individuals and society have entered the scene with the intensity of boom-town growth in both numbers and complexity.

The surge of technological and scientific advances, matched by moral quandaries and ethical dilemmas, has challenged the health care system to strike a balance between conflicting medical needs and their spiraling costs.

And as Jane and John Q. Public are forced to grapple with a broad range of health care choices for themselves and their families, they must also reach beyond their rights to question professional responsibilities and social interests. And they ask questions of themselves and society.

Dare we turn our backs on the millions of American wage-earners who can neither afford health insurance nor qualify for government assistance, and thus remain medically homeless?

...it provides citizens with a common voice, a common purpose...

What do we say to the booming elderly population of friends, family, and neighbors, their lives prolonged by medical miracles, now at the height of their vulnerability, who are in jeopardy of having care sharply limited? Who decides how scarce organs donated for transplantation should be rationed? Who has the wisdom, medical integrity, and the right to weigh the value of one life against another? Have we as individuals and community forgotten to value compassion, justice, and humaneness as integral components of health care.

Palliative care, comfort care, quality of life and death, once in the private domain of the hospice model of care, have gone public. Informed consent, DNR, CPR, the elitist language of the medical profession — all new entries in citizens’ vocabulary of Patients’ Rights, Doctor-Patient Relationships, Advance Care Planning — have tilted the balance of power in end-of-life care.

Clearly, a disquieting atmosphere in which not one sector of our diversified society has escaped having to face these challenges. Professional health-care providers, insurers, policymaking pundits, medical ethicists — each driven by their own special interests — network with their constituencies and establish their own bailiwicks.

But what about our friends Jane and John?

Concerned citizens nationwide, threatened by the swelling tide of polarization, misplaced priorities, and social inequities in the health-care system, sought a venue in which to make their presence felt at the centers of power.

In 1982, Oregon, a health-care trendsetter, organized an extra-ordinary grass-roots initiative to empower citizens to participate effectively at the local and state levels. Nonpartisan, non-profit, dedicated to public involvement, it provided citizens with a common voice, a common purpose for the common good.

In short order, community health-decisions groups across the nation began to demonstrate that when citizens want to understand, debate, and be engaged in personal health-care decisions, they can become stakeholders in public-policy deliberation and development.

By 1988, American Health Decisions (AHD), the Health Care Grass Roots Voice, a national consortium of state citizens’ groups, had been founded by a core of activists from ten states. Acknowledged as the national leader in promoting values-based citizen choices in health-care policy, as a collaborative proactive organization it provides a network of professional resources. By actively enhancing communication and sharing of information and expertise among member states’ groups, it strengthens and nurtures each organization.

Early on, AHD recognized that unless an active, informed public is involved, left to the experts alone, serious health-care problems could not be resolved satisfactorily.

Increasingly, newly formed havens for grass-roots participatory democracy were tapping into diverse groups, bringing people together to clarify individual and community values, to deepen and broaden their perspectives.

From coast to coast, north to south, state health-decisions groups had become catalysts for change, their participating citizens agents for change. Tens of thousands of citizens became involved; community responsibilities were activated.

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In Massachusetts, people gathered in town meetings to discuss the need for universal access to health care. In California, educational programs on the use of Advance Directives reached thousands throughout the state. In Vermont, the issue of health-care resource allocation was debated at community public forums. In Georgia, at focus group meetings, citizens speaking their own minds identified what they value in a health care system. In Oregon, a special health-decision project demonstrated how much citizens truly wanted fair and equitable distribution of health care and resources. The New Jersey Citizens' Committee on Bio-Medical Ethics first saw the light of day in the living room of its founder, Mary Strong, where six similarly concerned enthusiasts were transformed into a statewide organization.

Striking in this overview of stepped-up health care activity momentum was one significant disturbing revelation: New York State was conspicuous by its absence. Given New Jersey's success, it seemed inconceivable — unconscionable — that its next-door neighbor New York had not yet found a way to muster the troops to follow suit. Seizing the moment, in October 1989, a thirty-member steering committee was convened to test the possibilities of going forward. Several meetings later, a smaller group emerged, with motivation and commitment playing the key roles in the decision to go with the consequences on a trial basis.

Homeless, staffless, fundless, but not friendless, this smaller but ever more tenacious group survived. As yet organizationally unstructured, we were generously provided (read blessed) with meeting sites by both the Governor's Task Force on Life and the Law, and a local Unitarian Universalist congregation. By October 1990, now officially named, the New York Citizens' Committee on Health Care Decisions (NYCCHCD) with a Board of Directors and Officers (with myself as the Chair), was ready for action but had no place to hang its hat. Thanks to the National Health Council we had the use of a desk, telephone, mail service, and other such facilities until August 1991, when the Council's move to Washington, D.C. set us on a search for a permanent base. Not even the most fanciful fantasies could have envisioned a site as perfect as our new one at the New York Society for Ethical Culture building.

Legal work done pro bono, incorporated as a membership not-for-profit organization with 501-(c)-3 IRS status, we shifted into high gear to bridge the gap between citizens' health-care needs and values, and those of caregivers and lawmakers.

Our mission statement put a face on our organizational persona: "The primary purpose of the NYCCHCD is to promote exploration of the ethical issues in health care presently facing individuals, institutions, and policy makers; and to provide a mechanism by which these issues can be broadly communicated to the society at large as well as to policy makers at the state level." In short, this can be read "to create a framework for public policy to be fleshed out by an informed public involved in the process, with emphasis on the individual."

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While many advocacy organizations exist to promote one specific issue, the Citizens' Committee's uniqueness is two-fold. It lies in its non-partisan stance on a panoply of big-ethics issues and in its concentration on the "people" — the citizens who want to listen, to learn, to have their say. This is the road to Citizen Empowerment we have chosen and continue to travel with no distracting detours. In the true grass-roots tradition, we wanted to know what ordinary citizens talk about, and why.

As with any fledgling organization, the Citizens' Committee's mobility remained to be tested and proven. However ambitious our intentions to emulate our more established, expansive, financially endowed state health decisions colleagues, reality reduced long-range strategies to short-term plans. Statewide in intent, citywide in capability, we functioned solely on a

voluntary basis throughout the first year, organizing, setting program goals, providing a series of meetings in the metropolitan area.

Early on, we learned that there are no magic wands to wave to instantaneously provide groups of citizens eager to work to make a difference in health-care policy outcome. Citizens must organize themselves or be organized for meaningful participation, a responsibility to be shared with community leaders at the grass-roots level.

For civic involvement, it is only when the "how," the methods to encourage participation begin to work, that the "what," the program goals, will be achieved. These goals typically common to health decision programs are; to educate the public, to extract information about citizens' values, and to build community responsibility around given issues. To date, our experiences have shown that issue conferences, public forums, local meetings, study groups, and workshops are most successful. We have yet to mount a focus group values survey project.

A rundown of our activities astounds even those of us immersed in planning and implementing on a daily basis. Our major forums assemble health-care providers, attorneys, ethicists, clergy, and concerned citizens to explore hot-button issues. Diversified in scope, and enhanced by collaboration and networking, we bank on creative style as well as content for popular appeal.

To wit: "Physician-assisted Suicide: If it Were Legal Would it Be Workable" played to a full house in 1994 and called for a revisit to the issue in 1996 with "Last Rights: Should the Medical Profession Help Competent People With Terminal Illness End their Lives on their Own?"; "Managed Care: Panacea or Pandora's Box?"; a colloquy exploring the issues raised by the rise of Managed Care; "Way to Go -Everything You Need to Know to Control Care and Decisions near the End of Life"; "Who Supports the Patient? A Collaborative Discussion of the SUPPORT Study." All examples of innovative approaches to critical issues, all audience-producing.

Two inspiring presentations in our Annual David Finley, M.D. Memorial Colloquium were: "Don't Manage Me, I'm No Case," Dr. Robert Butler's account of the changing medical scene; and "The

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Human Agenda In Health Care” featuring Anna Quindlen’s public and personal views of medical care experiences.

Our semi-annual Let’s Talk discussion series never fails to meet expectations of our members at over-subscribed workshops on provocative topics — “Proxy at the Bedside”, “Hospice at the Crossroads”, “Caring for the Elderly”, “Who’s Caring for the Caretakers?” and “Am I My Parents’ Keeper?” Our annual Members Reception attracts marquee speakers and SRO attendance.

Never able to refuse a request for a speaker, our Community Outreach programs have taken us into high schools, senior citizen’s centers, hospitals, nursing homes, houses of worship.

Not surprisingly, our organization has taken on a life of its own. Our membership has shown significant yearly growth both in numbers, interest and support. Networking with local similarly-purposed groups has broadened our constituency, and enhanced our visibility and reputation. Linkages with compatible statewide organizations with a view to expansion is now a top priority. Our goal to provide all New Yorkers with opportunities for empowerment has begun to be realized on Long Island, and in Westchester and Rockland Counties.

As a typical not-for-profit entity, the NYCCHCD relies on membership dues, program registration fees, and project-driven funding. We have been particularly fortunate in capturing the attention of several family foundations for unrestricted operational grants. Our greatest and latest pride of accomplishment is in the funding grant from the Open Society Institute, Project on Death in America, for our two-year project, “Senior Partners In Health: Learning to Use the Physician-Patient Relationship as a Prudent Patient.” Further proposals for project funding are being developed for Managed Care Focus Groups, and for a “Day of Ethics” program on big-ethical issues in the high schools.

Time and again we’ve been asked, how can your small band of miracle workers be so timely, so on-target with all you do? What gives you such keen sensitivity to individuals and communities?

Here again, the answers are straightforward.

- We never stray from our mission
- We take a neutral, impartial stance
- We focus on people
- We face their challenges from their viewpoints and in real terms

- We strive for equity in addressing relatively intangible values and concrete purpose
- We are firm in our belief that only an Informed Citizenry can be an effectively Involved Citizenry
- We entrust education, collective deliberation, communication with the keys to Citizen Empowerment

In all of the above and more, as we reflect on the grassroots approach, we are always mindful that, while there are no perfect solutions — just preferable

ones — they must give voice to all clusters in our society.

Beatrice Greenbaum, HA’82, is Chairperson and Executive Director of the NYCCHCD. She is also an active participant in, and a board member of, numerous committees and organizations committed to the delivery of quality health care. She is the recipient of several awards including the “Liberty Bell Award” and the 1997 Health Advocacy Award for her outstanding service to the community in the field of health advocacy.

Polly Rothstein: Clout & Credibility

by Deborah Hornstra, M.A.

Polly Rothstein’s desk is, as usual, overflowing with papers, but she finds everything she needs easily. The walls of her White Plains, New York, office are covered from floor to ceiling, one with color photographs of birds she has sighted, the others with clippings and memorabilia from Rothstein’s long career as an advocate for the right to abortion. As founding president of the Westchester Coalition for Legal Abortion, an organization that dates back to Roe v. Wade, Rothstein is probably the single most important reason why Westchester is and always has been steadfastly pro-choice, despite the county’s otherwise deserved reputation for conservatism.

*“It’s a numbers game,
and numbers make power.”*

The consummate grass-roots organizer, Rothstein has made it her personal crusade for 25 years to use the ballot box to ensure abortion remains a legal medical procedure in New York State. The Coalition’s database comprises 70,000 households, or a full third of the county’s electorate. The list was compiled using what Rothstein calls “massive systematic telephone canvassing of all registered women voters whose phone numbers we could get.” (The first thing she did when this reporter entered the room was add

my name and unlisted phone number to her files!)

Why is Rothstein so focused on the list? “It’s a numbers game, and numbers make power,” she says adamantly. In the years immediately following Roe v. Wade, the Coalition kept its names on paper, but in 1980, Rothstein computerized the process (originally using a mainframe), which made it easier to manage and expand the list. With increased numbers, says Rothstein, “Our credibility soared. It was clear that clout matters.”

“The key to keeping abortion legal,” declares Rothstein without hesitation, “is electing the correct people.” In the November 1997 race for County Executive, Westchester voters were courted by two candidates who both claimed to be pro-choice. The Coalition, however, declined to endorse local mayor Ted Dunn, who had spoken out against “partial birth abortion” and in favor of more restrictions on the procedure. (Rothstein later said Dunn threatened her with retribution for withholding her endorsement.)

Instead, the Coalition backed only longtime county clerk Andy Spano, whose prochoice record was not in dispute. Coalition staff and volunteers made over 50,000 phone calls from their seventeen phone lines in the weeks prior to the election, and Spano roundly defeated Dunn. It’s just the latest example of the political influence Rothstein and her Coalition wield in Westchester. Every election, the county is blanketed with the Coalition’s bright yellow “Pro Choice Voting Guides.” The guides spell out each candidate’s position on abortion, which Rothstein calls a “gut issue, a bottom-line issue.” The lat-